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Theorising how Art Gallery Interventions Impact People with Dementia and their Caregivers

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Abstract

Dementia refers to a variety of diseases that are characterised by cognitive difficulties and an overall decline in daily living skills. Psychologically-informed arts and health programmes may be particularly beneficial ways of improving the lives of people with dementia and their caregivers. This study sought to better understand how programmes at contemporary and traditional art galleries might play a role in the lives of people with dementia. Participants included 12 people with mild to moderate dementia, their 12 caregivers and 4 gallery facilitators. Those with dementia and their caregivers were engaged in art-viewing followed by art-making over an 8 week period. Data, collected through post-intervention interviews with participants, field notes and extensive written communication between the facilitators and research team, were analysed using grounded theory methodology to theorise how gallery-based interventions affect people with dementia and those who care for them. The emerging theory has four primary components: the art gallery is seen as being a physically-valued place that provides intellectual stimulation and offers opportunities for social inclusion that can change how dementia is perceived. These components coalesced to create positive emotional and relational effects for those with dementia and caregivers. The resulting theory has potential implications for the use of gallery-

based programmes in dementia care within public health, healthcare and museum/art gallery policy and practice.

Key words: dementia care, art galleries and museums, creativity, caregivers, public health, arts and health, grounded theory

Acknowledgements:

Introduction

Dementia has become a key health and social care issue for the 21st century as a result of increasing life expectancies (World Health Organisation, 2012). It is classified as a cluster of symptoms related to neurological changes that contribute to cell death and impaired functioning of brain cells. The biological and psychological symptoms associated with dementia include cognitive difficulties, an overall decline in daily living skills, changes in behaviour and mood. There is no cure for dementia and pharmacological treatments at best delay progression (Ford, 2014; Raina et al., 2008). Thus, in order to challenge the sole narrative of dementia from one of hopelessness and despair to one imbued with different metaphors and possibilities (Zeilig, 2013), attending to the social and psychological wellbeing of people affected by this condition is essential (Beard, 2012; Cohen, 2000). The needs of those who care for people with a dementia have been increasingly recognised (Crombie, Irvine, Elliot, & Wallace, 2007). A recent UK government policy document, *Living Well with Dementia* (Department of Health (DoH), 2009), highlighted the importance of family members as a resource for people with dementia and estimated that “they provide over £6 billion a year of unpaid care” (p. 50). Evidence has shown that being a family caregiver of someone with dementia can be associated with higher levels of depression and isolation (Schulz & Martire, 2004).

Art gallery and museum programmes

Art galleries and museums are popular settings to offer programmes for individuals with various mental health issues (Shaer et al, 2008). Art may be a particularly useful form of intervention for those with dementia since aesthetic responses appear to be preserved for some time after the onset of neurological disease (Halpern et al., 2008; Stewart, 2004), thus visual art appreciation and art-making

offers an area for continued exploration. Participation in creative arts has been shown to enhance social and psychological wellbeing of people with a diagnosis of dementia and their caregivers (Kinney & Rentz, 2005); increase enthusiasm, confidence, enjoyment, and social contact (MacPherson, Bird, Anderson, Davis, & Blair, 2009), and decrease depression (Musella et al., 2009). Whilst such interventions demonstrate some of the benefits of creative arts participation, there is further evidence to show that art projects can promote a sense of community and challenge stigma (Howells & Zelnik, 2009) and this may require re-considering the use of traditional care settings. Health psychology (Camic, 2008) and public health (Camic & Chatterjee, 2013) interventions based around creative arts offer the opportunity to provide support to those with a dementia in non-stigmatising community settings and thus work at an individual, caregiver and community level.

MacPherson et al. (2009) developed a six-week programme at the National Gallery of Australia that included people with mild to moderate dementia and family members. Findings implied that the intervention prompted the discovery of residual abilities, enjoyment, sparked new interest in art and increased social contact. Caregivers described participants to have enjoyed the sessions and been enthusiastic, but no long-lasting changes were reported. Observations made by facilitators noted that participants' memory was stimulated within the group (e.g. recognising paintings and other participants), and they appeared confident and enthusiastic in the gallery setting. Using quantitative content analysis Eekelaar, Camic, & Springham (2012) explored the impact of viewing art and making in an art gallery context on verbal fluency and episodic memory over three sessions but also reported on themes arising from post-intervention interviews, which highlighted social benefits of being with the

group, personal effects of “becoming their old selves” (p.7) and the value of sharing an experience between the person with a dementia and the caregiver.

Camic, Tischler, & Pearman (2014) used a mixed-methods pre post design that built on the work of MacPherson et al. and Eekelaar et al. but measured quality of life, daily activities and caregiver burden across programmes at two different art galleries. As in some the aforementioned studies, participants took part in an art-viewing and art-making intervention facilitated by artists or art educators at one of two galleries. The study reported non-significant quantitative results but a thematic analysis highlighted three main themes: social engagement (social aspect of group and caring relationship), cognitive capacities (engagement, new learning, memory), and valuing the art gallery setting (social inclusion, feeling valuable, engaging with artwork, intervention structure and positive comparison to healthcare services).

The present study

The present study sought to develop a theoretical understanding of how the process of viewing and making art in the social and physical context of an art gallery environment impacts people with dementia and accompanying caregivers. A better-developed understanding of this process could influence future research and help to further refine subsequent involvement of art galleries and museums in health and wellbeing improvement programmes thus supporting different national dementia strategies.

Method

Participants

Twenty-four participants (12 with dementia) were drawn from similar art gallery-based programmes (14 and 10 participants, respectively) at two distinctively different galleries in diverse geographical regions of the United Kingdom (dementia

participants age range, 58 – 94 years; 17 White-British, 4 White-Europeans, 2 British-Asian, 1 Black-British; 15 women); all participants who were approached consented to participate. Inclusion criteria were a diagnosis of dementia within a mild to moderate range, age ≥ 55 , and no significant mental health symptoms as identified by the caregiver. Exclusion criteria were physical incapability to attend, a severe mental health problem or life threatening illness. To determine inclusion within a mild-to-moderate range of dementia, the Addenbrook's cognitive examination revised (ACE-R) (Larner, 2007), incorporating the mini-mental status examination (MMSE, Folstein, Folstein & McHugh, 1975) was administered along with the neuropsychiatric inventory (NPI-Q, Kaufer et al., 2000). At initial screening there were no statistically significant differences between participants at either site on MMSE, ACE-R or NPI-Q scores. In addition to programme participants, four gallery facilitators (two from each gallery) were interviewed. The research adhered to the British Psychological Society's research ethics guidelines and approval to conduct the study was granted by a Canterbury Christ Church University Ethics Panel.

Procedure

The gallery intervention consisted of eight two-hour group sessions over an eight-week period at both sites. The sessions were divided into two sections: one hour of art-viewing and discussion followed by one hour of art-making. In the art-viewing, an art educator guided discussion about two or three pieces of art within the gallery; for part of sessions 5, 7 and 8 participants chose one painting or object they particularly liked and in dyads discussed this piece of art. After art-viewing the group moved to a studio for art-making, which was facilitated by a professional artist who had experience working with older adults; the theme of each art-making session was influenced by the paintings/objects discussed in the preceding viewing session. Each

week different art materials were provided depending on the focus of the session and included water-based paints, pastels, coloured pencils, collage material, glue, quick-drying modelling clay and printmaking supplies. Art-making consisted of the following: painting images and shapes, building abstract and figural sculpture, making lino prints, and constructing collages relating to feelings and emotions evoked by the art. Tea and biscuits were also provided during the art-making component.

After written consent was obtained, semi-structured interviews were conducted by the first and third authors of people with dementia and caregiver dyads 2–3 weeks after the groups ended; the interviews, which were audio recorded and transcribed, occurred in the participant's home and lasted 50–90 minutes. The researchers who attended each session at the two gallery locations kept detailed observational field notes and maintained frequent email communication, discussing various aspects of the project that took place amongst the researchers and facilitators. Further semi-structured interviews (30–60 minutes) were conducted with the programme facilitators by the second author.

Table 1 here

Data analysis

Data sampling followed Strauss & Corbin's (1998) process beginning with indiscriminate open sampling, followed by relational and variational sampling, where purposeful choice of people, sites or documents maximised opportunities to elicit data on variations along dimensions of categories. Theoretical sampling, which involved choosing the sites (contemporary and traditional art galleries), documents (interviews, field notes and an email blog) or people (those with dementia, caregivers and facilitators) that exploited opportunities for categories to develop followed. Data triangulation, a process that increases the validity of qualitative data through the use

of multiple data sources (Jick, 1979), included data sources in Table 1. Analysis was assisted by NVivo software (version 9). There is some debate about whether theoretical saturation or “theoretical sufficiency” (Dey, 1999, p. 117) should be aimed for in grounded theory. As this study developed it seemed more appropriate to use theoretical sufficiency as a benchmark for theory development in consideration of the multiple, but finite data sources.

Quality Assurance.

In conducting the study the research team strove to remain reflexive throughout by being aware of their own perspectives and the potential impact this could have on the project (Fischer, 2009, pg. 584). The authors used research diaries to record their responses and reactions throughout the study and to monitor impact on analysis. In addition, each stage of analysis was systematically recorded and the records and samples of coded transcripts were discussed among the authors until all parties were satisfied that the interpretation of the data and that the conclusions drawn were plausible. A credibility check was undertaken by the first and second authors through presenting the developed theory to two individuals with no prior knowledge of the area and actively soliciting feedback.

Results

Initial open coding resulted in 155 open codes. Further analysis was carried out using the constant comparative method (Glaser & Strauss, 1967), and codes were interrogated for similarity or connections to other codes resulting in a reduction to 73 open codes. Through this process, connections between the open codes were identified and sub-categories/categories developed. For example, the open codes of art becoming accessible, overwhelming, and feelings of discomfort contributed to the subcategory of “competency” as they reflected different perspectives of how the

intervention affected a sense of competency. Initially 15 categories were established which were iteratively reduced to 8 categories, encapsulating numerous open codes. This process involved eliminating categories that were not relevant to the theory; for example, one category was “practicalities” in which participants reflected on ways to improve projects practically such as seating and accessibility. Whilst informative for future interventions this was not deemed directly relevant to the development of an overarching theory.

The next step in the analysis examined each category to determine whether it was comprehensible, distinct from other categories, and could be considered to have sub categorical properties (Glaser & Strauss, 1967). This aspect of the analysis, which again made use of the constant comparative method, resulted in the elimination of some categories and the incorporation of others into four superordinate categories (Table 2). In addition, some categories became subcategories, “respite” was integrated into “social relationships” as it highlighted the way in which the intervention enabled a different relationship with the person with dementia, which was in turn experienced as a form of respite from the caring role.

Table 2 here

Subcategory descriptions

The following quotes are attributed to both place, (traditional gallery (D) or contemporary gallery (N)) and participant category ((P) person with dementia, (C) caregiver or facilitator (F)) (e.g. a person with dementia at the contemporary gallery would be designated N-P).

Gallery setting.

Ordinary users of a community place. Participants noted benefits of the art gallery being open to the public at the time of their group: “It made you feel part of a

larger group that were appreciating the art.” (D-C). There was a sense of normalisation with one facilitator mentioning, “I liked the way it wasn’t closed because passers-by would often slow down and benefit from the exchange that was going on and it stops people from feeling stigmatised” (N-F).

The nature of the public setting led gallery visitors to overhear group discussion. One facilitator noted that “lots of the general public started to get involved as well, which for me was reassuring because it made me feel that what I was doing with them wasn’t for people who were ill or different”(D-F). The contrast between the gallery environment and more usual clinical settings was also noted:

“Very often...activities...might be tailored to reminiscence or at day centres or up at clinics, people are often talking to you, to both of us, as we are people in the situation we are in, rather than as equals. And I was very conscious I think at this gallery that we were with people, we were working together...People were treating you courteously as equals with something to contribute.” (D-C).

In this sense the people as well as the place enabled a sense of normalcy, equality and personhood.

Somewhere different. Numerous participants commented on the significance of being somewhere “so different” (D-C), “It lifts you into another world... I just felt released from the humdrum stuff at home” (D-P)

“It’s a nice little place for quietness to work, your brain will work” (D-P). Significantly there was a sense that it was about departing from the usual everyday activities/place, “It gave them a structure that was beyond their everyday structures” (D-F). This sense of difference was also linked to an event of value “It was nice to do something that’s different from being at ... so that in terms of, of going out and

experiencing different things and going into the gallery especially you know, um getting, you know lipstick on” (N-C).

A special and valued place. “It was a really luxurious experience...we were really privileged, very luxuriously treated, and being showed around, and the food, and the chocolate biscuits!” (D-C), “It’s beautiful space...it’s not just the art, it’s the space and all people being, behave in the museum, it’s very... people are very respectful I find in museums.” (D-C). This sense of a special and valued place seemed to generalise to the participants feeling special and valued, “And when you’re sort of our age there’s not many people really want to be bothered with you to be quite honest. But there you felt really welcome yeah” (N-P).

Intellectual Stimulation

Almost all participants commented on the learning experience of the group, “It was enlightening” (N-P), “I didn’t have any knowledge of art and I think it was fun, enjoying, discovery, learning” (D-C). One family caregiver underlined the significance of learning as opposed to reminiscing (a focus they had experienced in other support groups): “Even when your memory is not quite as good as it should be, your life isn’t only about reminiscing ...So that’s the difference with this kind of activity, because you feel its forward looking, it’s learning” (D-C). The same person went on to vocalise the importance of new learning despite the fact that the knowledge may not be remembered, “retaining what you have learnt becomes more difficult, but that doesn’t necessarily devalue the whole learning process, because the learning is an end in itself and it is enjoyable at the time...You are enhancing your life at the time” (D-C).

Art as a universal interest. A participant with a dementia reflected on why the art engaged her:

“Because it was a very natural thing to...the fact is that it is a subject, everybody is interested in. Art is what you see, it doesn’t usually require, you can appreciate it, because the whole of our existence in life is appreciating a view, what we see out of our eyes.” (D-P).

Another likened it to other areas people seem naturally interested in:

“I think art ...is definitely useful with people with memory loss basically because you can look at something and if it’s nice you just know you don’t learn that and...can talk about that about what he can see.” (N-C).

One commented on how art acted to enable a “normal” experience of learning rather than emphasising the caring relationship due to the experience of dementia:

“It’s a triangular relationship isn’t it, it’s between you, the facilitator and the object, and the object is the art. So here are two people functioning at the same level and exchanging conversation and having jokes and one of them is learning and the other is helping the learning...not just here am I with a problem, and here am I working with you and your problem” (D-C).

This quote articulates the way in which the art acted as a means by which to shift the focus from dementia and the caring relationship to the broader, non-clinical subject of art.

Competency. Various participants appeared to achieve a sense of competency through the experience: “The team was very encouraging. There was a man who was always belittling himself, then he stopped doing that” (D-C). Another reflected on “Getting more confident, yes there was no judgement” and that facilitators “made you feel as if you were welcome and not stupid if you know what I mean (laughter)” (N-P). One participant reflected on their own surprise at their abilities “learning with others and finding that I knew more than I thought I did. You can pull things up out

of your mind can't you given the right stimulus" (N-P). This was also noticed by the facilitators at both galleries:

"There are many different areas of expertise, and this is a nice forum I think for people to be intellectually stimulated and be stimulating; I learnt many new things yesterday, and I think it is nice we can learn from each other" (D-F).

There were clearly two sides to this, as some evidently compared themselves to their previous abilities, or those of others, with one individual reflecting on how "you probably feel you can't do what you could of done earlier" (D-P). Despite the experience highlighting losses in some abilities, all participants remarked on some aspect in which they felt more competent.

Engagement. Participants with dementia described how the experience "Opened one's mind really" (D-P) and "I was never bored at any point" (N-P). Caregivers also noticed differences in the person they cared for, "He got absorbed in things in a way that he probably doesn't so much these days...I think he was certainly concentrating more than usual. Both on the pictures and when he is doing the creative thing" (D-C). The engagement in the activity was considered particularly valuable given that caregivers recounted deterioration in motivation to participate in activities in daily life, "that is all peeling away you see, her interest in anything is going, and of course she is not doing anything domestic as I am doing it." (D-C).

The level of engagement appeared to be a surprise to one facilitator:

"I have been struck by the level of engagement of the group, who almost all remained fully focused for the whole 45-50 minutes of the tour...they have been my most engaged group of adults to date, I have given tours to including students, ladies who lunch, art historians, tourists, this group has been the most engaged" (D-F).

This surprise at the engagement of the participants linked in to how facilitators' perceptions changed.

Social Interaction.

Caregiver respite and support. Caregivers valued the time as an opportunity for a break from every day care obligations as well as peer support from those going through similar experiences:

“It has certainly helped me... you see others who have equal and worst problems than I do, it was relief for me in many ways, as it has been the only outing I would get....the rest of time it's just the two of us. For me it was an absolute gift.” (D-C).

Another caregiver said, “support, well, that made all the difference...everybody was so kind... there are days when you feel, boom! Your chin hits the floor, this support I am talking about is very important” (D-C). “They seemed to particularly like the contact with other caregivers and you know some of them started swapping numbers with each other so we found that they were kind of meeting independently of the group” (N-F).

Facilitators also spoke about how caregivers found a sense of respite at the gallery and were able to have a relationship with their loved one that was different to the caring role:

“One caregiver said that she enjoyed her relationship with her mother more, because she was relaxed when she was there. She didn't feel as though she was a caregiver. So it was respite time for her...” (N-F).

Interaction. The social and verbal interactions with others were valued by participants even if their memories of the intervention were hazy... “It was a chat really and a discussion mostly with...I can't remember his name?” (N-P). Caregivers

commented on the importance of the social interaction and group nature for the success of the activity:

“There are a lot of activities which are good for people in our situation...

But it isn't very easy to do it, sitting in your little place at home. The impetus isn't there. So to get together with a group of people and to interact like that, that's what I think makes it successful" (D-C).

Changed Perceptions.

Positive Affect. Almost all individuals with a dementia reported that it was “very enjoyable” (D-P, N-P). Caregivers also spoke of their partner enjoying it but also themselves:

“I thought it was actual fun, the doing of the stuff wasn't quite as..... it wasn't important that it came out like a Picasso, it... I am amazed that I liked it.” (D-C).

One facilitator reported that during the intervention a participant had said, “I don't know what I'm doing here, but I'm enjoying it!” (N-F) which aptly demonstrates how the intervention was enjoyable “in the moment” whether or not the experience as a whole was recalled.

Different view of dementia. “I found it a truly rewarding experience which has changed the way I think about people with dementia and their caregivers” (D-F). Facilitators were clear about how the project had dispelled some commonly held beliefs about dementia “the level of engagement of this group...is really, really remarkable...because...the stereotype of people with dementia is that they have low attention levels. This really is not the case with respect to this group on this project” (D-F).

“Perhaps the most impactful session for me was when two people with dementia facilitated a discussion... I couldn’t have imagined at the beginning that two people with dementia would not only make art and take part in the group but would be able to talk about it and facilitate a discussion about the works.” (N-F).

Caregivers also saw new aspects, “she sang a song in the gallery inspired by the skeleton of an armadillo, which was delightful and it took her daughter by surprise because she was so introverted” (N-F). Another commented on how other people had been surprised when seeing what their loved one had achieved, “She sat and drew me one day, many people since have seen it and remarked, “oh gosh this is terrific!” (D-C).

Inspiration to change. Many participants reflected on general outcomes of the group “It was helpful yes I hope it’s woken me up a little bit... that’s as much as I remember and I have still got this feeling of warmth” (N-P). However, these benefits were queried in regard to their importance given that the experience was not retained, which one participant aptly expressed, “that’s sod’s law¹ if you can’t remember” (N-P). Nonetheless, facilitators and caregivers at both locations had positive feedback about potentially longer term effects of the intervention: “Movingly, S felt that the experience had been ‘a rescue...bordering on life saving!’” (N-F) and

“I feel like this is wind beneath our sails now...given me some direction with my sister...I didn’t think I’d take to this but I do. I can see its value.

I keep notes and I am making changes at home.” (D-C).

Almost all planned to continue to visit galleries and many expressed a desire to continue with the creative, practical aspects, “It opened a door...yes we are going

¹ Sod’s law is a British axiom roughly meaning, ‘if something can go wrong it will and will do so at the worst possible time’.

...to do more activity related to art.” (D-C). Yet, different realities were also expressed by a person with dementia, “Somehow the urge is not there” (D-P) and by a caregiver, “I seem to just be able to get through every day doing all the stuff I need to do. I am not able to do stuff that is fun” (D-C). Another expressed, “I have no use for it, it’s not going to pay the rent, it’s like an indulgence... I would never set time to do it that’s the thing” (D-C). So whilst the experience was valued, and future visits planned, for some the burden of day-to-day care demands overshadowed perceived benefits of the gallery experience.

A grounded theory

The ideas and concepts discussed above were integrated into an initial theory (Figure 1). Theory development took into consideration the coding families described by Glaser (1978), which considered the causes, contexts, contingencies, consequences, covariances and conditions that need to be addressed: The special, valued and different context of the gallery setting enabled an intellectually stimulating learning experience to take place for both the person with a dementia and their caregiver; this stimulation contributed to feelings of engagement and a growing sense of competency. The intervention stimulated social interaction and positive affect, which, in turn, enabled a sense of respite in caregivers’ daily lives. The shared experience was often a new way of being with one another and caregivers saw something different in the cared for person, which positively affected the caring relationship. The effect or impact can be considered divided into effects at an individual, relational and community level. Both those with dementia and caregivers experienced positive affect changes (individual level) but also described positive effects of social interaction (relational level). For those caregivers describing high levels of burden and limited resources (e.g. transportation, other demands on time)

there were concerns, however, whether it would be worth the effort to attend future activities. Facilitators and other museum staff, along with caregivers, noted changes in their perceptions toward people with dementia, which possibly could be considered indicative of the potential for community and societal changes in attitudes toward dementia.

Figure 1 here

Discussion

This paper sought to develop a theoretical understanding of how the process of viewing and making art in the social and physical context of an art gallery environment impacts people with dementia and accompanying caregivers. The resulting theory acknowledges the significance of the “valued” setting, suggesting that whilst social interaction was a key factor, the art gallery experience and context, referred to by Smith (2014) as the “museum effect”, played an important, and perhaps decisive, role. Responses were similar whether from participants at a contemporary gallery looking at conceptual and installation art or at a traditional gallery, housed in a Georgian-era building, where 16th and 17th century European art predominated. One explanation of this is Winn’s (2000) view that a gallery should provide relief from roles or associations with sickness and become a source of pleasure and beauty. Indeed, some participants reflected on the importance of the gallery being a “special and valued” place away from the everyday activities of life. The centrality of community-based contexts is a longstanding tenet of community psychology theories (Levine, Perkins & Perkins, 2005) and this study offered additional support for their importance.

The stimulation of viewing and making visual art, in conjunction with a supportive group environment, created opportunities for individuals with dementia to

be perceived differently by their caregivers and gallery staff. Art gallery facilitators expressed changed attitudes towards participants with dementia, which appeared to be related to the opportunity to share an engaging experience with these individuals and to witness them making capable contributions in an intellectually challenging setting. It was also commented upon that members of the public attempted to join the groups at times, which led to speculation among the facilitators as to whether activities such as these could also lead to greater public awareness and volunteerism in dementia care and how people with a dementia might also join non-dementia specific gallery activities. As previously argued by Camic and Chatterjee (2013), this provides further indication that art galleries and museums can deliver supportive assistance to healthcare staff and policy makers by providing a broader base of caring opportunities whilst helping to develop ‘dementia friendly communities’ (Alzheimer’s Society, 2012).

The importance of “intellectual stimulation” has a familiarity to it in light of the increasing use of cognitive stimulation therapy groups (CST) (Spector, Orrell, Davies, & Woods, 2001; Spector et al., 2003). The skills of people with dementia are frequently underestimated or not valued, while there is often an over-emphasis on difficulties and problems; consequently, those with dementia can be presented with tasks offering low levels of intellectual stimulation or providing little sense of achievement (Malone & Camp, 2007; Perrin, 1997). Continuously low levels of emotional or cognitive stimulation can lead to boredom, disengagement and depression in people with early to middle stage dementia. In addressing these issues, Liebenberg (2009) argued that the mutual co-construction of meaning of images (i.e. visual art) contributes to a flattening of hierarchies and reduction in power imbalances thereby contributing to a feeling of value. This co-construction of meaning helped to

elucidate the link between the “intellectual stimulation” of looking at and creating art and of doing so within a “valued setting”, both of which are key components of our developing theory.

The third key factor of “social interaction” was perhaps the least surprising. Social engagement, and the resulting decrease in social isolation, has been recognised as an important component of wellbeing in older adults (Cherry et al., 2013), including those with dementia and their caregivers. In the UK, older adult mental health services within the National Health Service (NHS) tend to offer support groups to caregivers and individuals with dementia separately. One reason for the separation of caregivers may be that such groups are considered to provide an opportunity for respite and peer support. However, the present study found otherwise in that caregiver respite and support can be achieved even with the person with dementia present. Enjoyable, intellectually stimulating activities, such as viewing and making visual art, engaged both those with dementia *and* caregivers, thus providing an activity that they participated in together and which had a positive impact on their relationship.

The final component, “changed perceptions”, is perhaps the most disparate, but reflects how psychosocial outcomes reported in previous studies may have been achieved (e.g. Camic et al., 2014; Eekelaar et al., 2012; MacPhearson, 2011; Mittelman & Epstein, 2009). These changed perceptions included seeing a more “competent person” who *still* has the ability to create, to socially participate and to intellectually contribute, not necessarily at a pre-dementia level, but at levels not anticipated before the start of the programme. The changed view of those with dementia by caregivers and facilitators was a distinctive outcome that may help to explain the positive relational impact reported in previous studies cited above. Our

theory suggests that engagement with art (intellectual stimulation) within the gallery setting helped to change the perceptions of caregivers and gallery facilitators about what people with dementia were capable of achieving.

Research and clinical implications

The emerging theory suggested four critical factors: a “valued place,” “intellectual stimulation”, “social interaction” and “changed perceptions”. All four factors could be manipulated using an experimental design to evaluate the robustness of the theory and direct future research. Comparing the “valued setting” of an art gallery to viewing and making art in a different setting such as a hospital outpatient clinic would further differentiate the role of place and environment. Viewing and making art as a group intervention could be compared to reminiscence and usual care support groups in a three-armed pragmatic randomised controlled trial (RCT). It would also be useful to establish whether other types of interventions for people with dementia, such as support groups, could be improved simply by changing the setting, or if places of value could be created in a hospital or care home, for example. Creating places of value does not necessarily have to come at a high financial cost and could include setting aside a space for a modest art studio in a care home or hospital ward where staff and family could engage in creative activities with residents/patients. ‘Miniature museums’ with rotating objects on loan from local museums and historical societies could easily be developed, some of which could also be appropriate for object handling (Solway, Camic, Thomson & Chatterjee, 2015). More care could be taken in the overall aesthetic environment of the healthcare facility by providing artwork on walls (e.g. good quality reproductions purchased from local museums or original art on loan from local schools and university art departments). Interested staff could act as curators and further add to their own

professional development. And perhaps most importantly, policy decisions by healthcare trustees and governing bodies could mandate that hospital wards and residential care facilities are stimulating and imaginative places that allow for creative engagement between residents, staff and visitors.

Limitations

The sample only included people with mild to moderate stages of a dementia over the age of 55. It did not include people with more severe dementia. People involved in the study self-selected to participate and may already have had an interest in art, although when asked during interviews most participants did not express previous interest or participation in art activities within the past five years. Facilitators were available to clarify gaps or discuss ideas throughout the study, participants were not able to do so, which potentially limited aspects of theory development. For example, by going back to caregivers to see if their changed perspective toward the person with dementia was only evident during the intervention would have allowed further understanding about the nature of impact.

Conclusion

This study sought to develop a theoretical understanding of how art gallery-based dementia care programmes might impact people with a dementia and their caregivers. Offering programmes to people with dementia, in a valued place such as an art gallery, facilitated intellectual stimulation and social interaction, which in turn helped to promote positive affect, relational benefits and changed perceptions of dementia. The theory challenges commonly held misperceptions about the capacity of those with dementia to engage in complex material and offers new ways of thinking about psychologically-informed arts and dementia care for policy makers and practitioners within healthcare, public health and art gallery/museum sectors.

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Table 1

Data sources

Data Type	Participants	Length of interview/ word count
Interviews with caregivers and individuals with a dementia	12 dyad interviews	50 - 90 minutes
Interviews with facilitators	4 facilitators (as described above).	30 - 60 minutes
Email blog (facilitators and researchers)	4 facilitators, as well as the researchers contributed to a contemporaneous email blog	32,818 words
Field notes	Written by 2 of the researchers	Approximately 5,800 words (42 hand written pages)

Table 2

Superordinate categories and subcategories

Superordinate Categories	Subcategories
Gallery Setting	Ordinary users of a community place
	“Somewhere different”
	A special and valued place
Intellectual Stimulation	Art as a universal interest
	Competency
	Engagement
Social Relationships	Carer respite and support
	Interaction
Changed Perceptions	Positive Affect
	Change/Anticipated change
	Different view of person with dementia

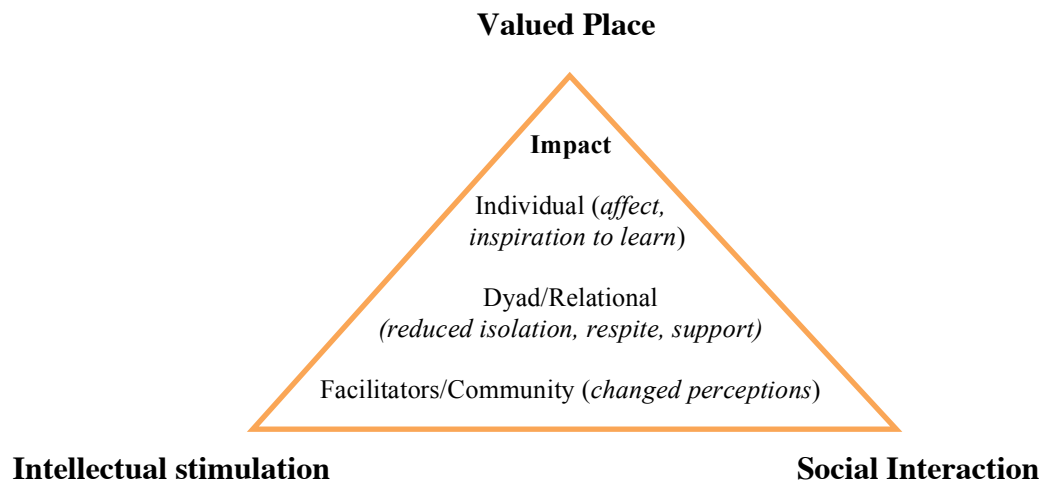


Figure 1. How an art gallery intervention affects individuals with dementia and their carergivers.